

# STATEWIDE INDEPENDENT LIVING COUNCIL (SILC)

MAY 31 – JUNE 1, 2007

GOVERNOR'S INN - PIERRE

MEMBERS PRESENT: Mark Arneson, Linda Biffert, Ryan Green, Vona Johnson, Grady Kickul, Thomas Kober, Patrick Czerny, Gaye Mattke, Betsy Valnes, Gary Wald and Marilyn Kinsman. MEMBERS ABSENT: Josia Fuerst, Philomine Moran, Jamie Mack and Betty Coon. OTHERS PRESENT: Matt Cain, Denise White, Sandy Neyhart and Shelly Pfaff. Interpreters were Julie Paluch and Marlee Dyce.

OPENING ACTIONS: WELCOME AND INTRODUCTIONS – Chairperson Tom Kober called the meeting to order at 1:35 p.m. He welcomed everyone in attendance and asked that they introduce themselves. MEETING PROTOCOL – Tom explained the meeting protocol. APPROVAL OF AGENDA – Tom noted there needed to be a few changes to the agenda. The first was to add two additional items under the Executive Secretary Report – (d) Summary of Questionnaire Results and (e) NCIL items; and the second was to move the Election of Officers to today's portion of the agenda prior to breaking into committees. The final changes were to delete the Association of CILs report and the WRDI report due to Ann Van Loan's absence. **MOTION TO APPROVE THE AGENDA AS AMENDED – MADE (M), SECONDED (S) AND CARRIED (C).** APPROVAL OF MARCH SILC MINUTES – Tom asked for a motion to approve the minutes of the last meeting. **MOTION TO APPROVE THE MARCH MINUTES AS MAILED OUT EARLIER – MSC.**

TIME FOR PUBLIC COMMENTS: Tom asked if anyone in attendance wished to make public comments. Seeing and hearing no response, Tom moved to the next agenda item.

Approved

09/18/07

DRS DIRECTOR'S REPORT: DIRECTOR'S COMMENTS – Grady started by asking the Chairperson if Betsy might provide an overview of the upcoming Youth Leadership Forum (YLF) event. Tom invited Betsy to do so. Betsy reported this will be the 9<sup>th</sup> annual event. It is being held on the campus of the University of Sioux Falls (USF). There have been some logistical challenges due to construction at USF, and the luncheon for which they've received 130 RSVPs, will be held at the Sioux Falls Convention Center. The YLF agenda includes community service opportunities, and an advocacy and disability culture session led by younger people active in the disability movement from neighboring states. Originally 38 students were accepts, but due to various reasons 35 of the 38 students are going to be participating in this year's event. Grady commented on how this is a life changing event for some participants, and he thanked Betsy for her update. Grady then spoke to the meeting on May 23<sup>rd</sup> between the State Plan for Independent Living (SPIL) signatories and the CIL Directors. He thanked the directors for participating in this meeting, and he stated that he felt it was a very good meeting and a renewal of commitment of all to the four core services and the delivery of independent living services to those needing them. INTRODUCTION OF DENISE WHITE – Grady reported that Denise started with the DRS on March 24<sup>th</sup>. She has extensive educational and experiential background, and she brings lots of strengths to the position. She will be working with the Freedom to Work Project, HMAD services, Assistive Daily Living Services waiver, the TAD program and independent living services. Grady invited Denise to talk a bit about herself. Denise said she is looking forward to working with the SILC. She has worked for the state for approximately 20 years – 15 years with the Department of Health in areas relating to children and adolescents and three years with the Division of Developmental Disabilities. She is a registered nurse by training. She stated her appreciation for the SILC's patience and support as she grows into this position. MEDICAL ASSISTANCE FOR WORKERS WITH DISABILITIES (MAWD) UPDATE – Grady stated how MAWD is a major outcome of the Freedom to Work Project. He reported that the

Approved

09/18/07

Medicaid State Plan was amended and approved by the Centers for Medicare and Medicaid Services (CMS) with an effective date of January 1, 2007. This is not only a significant accomplishment for the project, but it is also a significant change geared to benefit people with disabilities who are working or wish to work. The MAWD Implementation Team meets every two weeks, and it includes Department of Social Services, Department of Human Services and Freedom to Work Project staff. Grady reported that as of May 23<sup>rd</sup>:

- 82 people have been referred and initially screened
- 22 of these individuals did not pass the initial screening
- 60 passed the initial screening
- 53 have applied for MAWD
- 20 have been approved for MAWD and are on the program
- 16 applications are pending
- 17 applications were denied due to various reasons
- 4 of the applications that were denied did not meet severity of disability criteria – 2 are appealing these decisions, and these two cases are due to appear before an administrative law judge this week.

Once the appeals have been decided, the process will have come full circle. Grady reported that during the past five months, many bugs have been worked out, and he feels all has gone very well with the implementation. Initial projections for this program were that in the first year 75 people would apply for the program and 30 new individuals would be added to the Medicaid roles. Grady expects that the program will exceed those first year goals. Of the 20 individuals who are on MAWD, the majority of them are new to the Medicaid program. Grady stressed that this program is not a “cure all” for all people with disabilities, but it does keep some from falling through the cracks – people wanting to work and who are working. ASSISTIVE DAILY LIVING SERVICES (ADLS) WAIVER RENEWAL – The Department received word last Friday that the ADLS waiver has been renewed for another five years. There are presently 116 individuals on

the program and a waiting list of eight, with three new applications recently being received. The Division will be seeking significant expansion for this budget. Grady spoke to the extensive work, which has been done to develop a quality management strategy (QMS). The SILC has been written into this process as a group from which to seek advice and guidance on a regular basis. The IL movement has been a leader in the areas of consumer involvement, self-direction and consumer choice, and thus the SILC seems to be an excellent partner for the QMS activities of the waiver. The ADLS waiver was written from the beginning to have consumer directed services, and now Medicaid is seeking that approach. Grady said he received a lot of help on completing the waiver renewal process, and he thanked Gaye, Wanda Seiler, and Matt and his staff for all of their assistance. He closed by saying he is looking forward to the SILC's increased role with this program.

**RSA ON-SITE REVIEW/STAKEHOLDERS** – Grady reported that RSA is coming to the state in a couple of weeks. He reviewed some portions of their schedule, and spoke to the fact that when RSA came in the past, little if any time and attention was directed to Part B funded services and it's been well over 10 years since a Part C CIL had an on-site review. He drew specific attention to the stakeholders meetings for DRS and DSBVI, as well as the planned sessions with the CIL directors, SILC members and consumers of HMAD and TAD programs. He shared that CIL directors have been asked to provide staff with the names and contact information for up to five consumers of the HMAD and/or TAD programs by June 4<sup>th</sup>, so staff can then send out a letter to them about the pending RSA contact and the purpose of these contacts. The IL stakeholders call will involve Tom, as part Chairperson, the incoming SILC Chairperson, Gary as the CIL directors representative on the SILC, Denise, Shelly and himself.

**SILC SUPPORT STAFF AGREEMENT** – Grady shared the Division's level of satisfaction with the Coalition's service to the SILC and the Board of Vocational Rehabilitation. He read the last sentence of his letter to the Coalition, and upon completing his comments; Tom echoed his comments on behalf of the SILC. Shelly spoke to Lorie's leaving her employment

with the Coalition, and the reality that for a while; she and Colette will be carrying out all the duties until the organization determines how it wishes to proceed with its staffing pattern. Shelly gave her assurance that one thing that will not change is the Coalition's commitment to providing the highest quality of services to them.

DSBVI DIRECTOR'S REPORT: Gaye invited Sandy Neyhart, DSBVI Program Specialist, to begin the report by providing an independent living services update. Sandy addressed the CCTV (closed circuit televisions) lease program. There are 137 people who have CCTVs in their homes. They are older individuals, and currently DSBVI is completing a survey of these individuals. Sandy reported that they are noticing that individuals with CCTVs are less in need of regular contact with the agency, which is a good thing, as they are more fully independent in completing various daily living activities. There are additional CCTV units in the assessment centers in locations throughout the state. This program and technology are getting wide exposure through the Capitol for a Day events. Sandy then reported on the division's peer support activities. She shared that the Vermillion group will be touring the Rehabilitation Center for the Blind. The Watertown group is seeking a new leader, and a woman in Hot Springs is seeking to start a group, but enough people have not shown interest at this time to begin a group. Sandy reported there are about 20 groups presently up and running. Gaye thanked Sandy for her commitment to these peer support activities. A question was asked if the CCTV program is negatively impacting the total caseloads of the independent living program, and the response is that these numbers are remaining stable. DIVISION UPDATE – Gaye reported that the third week of July will be "Transition Week" at the Rehabilitation Center for the Blind in Sioux Falls. There will also be activities based outside the center, and there will be a beep ball event and picnic, which will provide the youth with an opportunity to connect with adults with blindness and visual impairments. Gaye circulated an invitation for the beep ball event and picnic. BOARD UPDATE – The next Board of SBVI meeting is scheduled for June 22<sup>nd</sup> in Pierre,

Approved

09/18/07

directly after the RSA review so she expects the outcome of the review will be a major portion of their focus. Gaye reported that Pat Czerny's term on the board is ending in June, and he has decided not to pursue another term. They have been in the process of recruiting nominations for vacancies. Gaye will serve as the Board of SBVI liaison to the SILC for the foreseeable future. Gaye thanked Pat for his service on the Board of SBVI and on the SILC.

DRS IL PROGRAM SPECIALIST REPORT: Denise provided this report. FY07 Budget Update – Denise reviewed the numbers as of the end of April (see attached). Even though they show some unexpended monies, staff is estimating that all the funds will be expended by the end of May. FY08 Budget – Denise reviewed the approved budget for the coming state fiscal year and the report format (see attached). No questions were raised at this time.

SILC EXECUTIVE SECRETARY REPORT: Shelly provided this report. ANNUAL CIL STAFF TRAINING – Shelly handed out the results of the questionnaire participants completed (see attached), and she reviewed some of the report highlights. She indicated that the training format we have used for the past two years seems to work very well, where we ask one of the CILs to provide a portion of the training. She also spoke to the value of the session beginning the conversation on the four core services. She invited Matt and Gary to provide comments. Their comments were supportive of the current approach to training, saying that staff feels this truly connects with what they are doing on a day-to-day basis. SILC NOMINATIONS PROCESS – Shelly reviewed the nominations process and reported that 10 nominations were received. Staff is continuing to develop briefing documentation and letters for forwarding on to the Governor. Once that has been done, copies of related information will be shared with the SILC. SILC/DRS/DSBVI PUBLIC MEETINGS – Shelly provided an overview of these meetings, reporting the number of participants, and the results of their responses to the questionnaire on what independent living services need to be included on the new

Approved

09/18/07

State Plan for Independent Living (SPIL). The top responses were: personal assistance services, transportation services, youth and transition services, rehabilitation technology services, assistive technology services, housing, home modifications and shelter services and recreational services. Shelly cautioned that this was a small sample, and anything but scientific, yet it is a snapshot of what some believe is important to include in the SPIL. It was also shared that some participants were referred to CILs following the meetings, and some in attendance had little knowledge or experience with IL services. SUMMARY OF QUESTIONNAIRE RESULTS – Shelly explained that following the public meetings, the CIL directors were contacted and asked to assist in sharing the questionnaire with consumers to gather their input on what services need to be included in the new SPIL. The responses were primarily from the eastern and central portions of the state. Shelly handed out a report on the results (see attached). Consensus was again that this is one piece of information that will be useful as we begin the writing of the new SPIL. NCIL ITEMS – Shelly shared information related to the SILC identifying a proxy vote for the NCIL annual meeting. Since Mark is representing the SILC at the conference and meeting, **MOTION THAT MARK ARNESON HAVE THE SILC'S PROXY VOTE AT THE NCIL ANNUAL MEETING – MSC.** Shelly apologized to Tom, indicating that she had two additional pieces of information that she would like to share with the members. Tom invited her to do so, and she handed out a memo from RSA indicating the recipients and amounts received of Part C funds for FY08. She then handed out an invitation to a retirement party for Lynne Cain. A member asked if it would be OK if she picked up a card for members and staff to sign tomorrow that would then be sent to Lynne. Consensus was that this was a good idea.

**ELECTION OF OFFICERS:** Tom asked Grady to take over at this point in the meeting. Grady explained how tradition has been that the SILC's Executive Committee presents a slate of nominees for the officer positions. Nominations are then sought from the floor. At this

Approved

09/18/07

time, Grady presented the nomination of Ryan Green for Chairperson. He asked three times for nominations from the floor. Hearing none – **MOTION TO ELECT RYAN GREEN AS SILC CHAIRPERSON – MSC.** Grady then presented the nomination of Linda Biffert as Vice-Chairperson. He again asked three times for nominations from the floor. Hearing none – **MOTION TO ELECT LINDA BIFFERT AS SILC VICE-CHAIRPERSON – MSC.** Grady next presented the nomination of Jamie Mack as Member-at-Large. He called three times for nominations from the floor. Hearing none – **MOTION TO ELECT JAMIE MACK AS MEMBER-AT-LARGE – MSC.** The elections concluded at this time, and the meeting was turned back over to Tom.

Ryan Green asked Tom to come forward, and he presented Tom with a plaque from the SILC thanking him for his years of service with the SILC and on behalf of South Dakotans with disabilities seeking to live independently. Tom thanked the SILC for this gift and for the opportunity to serve.

At approximately 4 p.m., the meeting broke so members and staff could meet in the Budget and Strategic Planning/Advocacy Committees. All were reminded that the meeting was scheduled to begin the next morning at 8:30 a.m. and they would be done today once their respective committees had concluded their business.

The meeting reconvened at 8:30 a.m.

Tom again asked all to introduce themselves so Linda would know who was present today. He also reviewed the meeting protocol and asked for any public comments. Hearing and seeing none – he moved on with the agenda.

**COMMITTEE REPORTS:** BUDGET – Gary reported out for the committee. The role statement they developed reads – “The role of the Budget Committee is to make recommendations to the SILC on the SILC budget based upon the activities of analyzing funding needs,

Approved

09/18/07

executing and continually analyzing the funding formula adopted by the SILC, and monitoring the CILs for performance.” There was some conversation on whether or not it is the role of the SILC to monitor the CILs. It was shared that both committees had conversation on this topic. It was agreed that the intent of the SILC’s monitoring is to ensure that services are being provided as intended and that funds provided in support of those services are used appropriately. One example of the type of monitoring they might do is to review 704 data to identify service trends and needs. The result of their monitoring efforts is, again, to ensure that appropriate services are being provided to eligible individuals, not to dictate how CILs deliver those services or how they carry out their day-to-day operations. The Budget Committee also spoke about the new “draft” SPIL goals. They recommended changing “Goal 3” to read, “Ensure that staff are qualified, educated on the independent living philosophy, and provide independent living services, including the four core services – advocacy, information and referral, independent living skills training and peer support.” They further recommended, “Goal 4” read, “The SILC, DSUs and CILs will mutually collaborate with other State, tribal and local agencies and organizations.” There was lengthy conversation about the need to keep “Goal 5,” and the precedence it sets in terms of identifying other specific portions of the larger disability community. The final consensus was that as the new SPIL is drafted, staff will attempt to include strategies and actions specific to meeting the needs of persons with blindness and visual impairments under the goals. Key to allaying any concerns that might result from this approach will be the clear communication that the intent is not to lessen the importance and priority of services for people with blindness and visual impairments, rather an effort to be inclusive in the approach to the delivery of IL services. STRATEGIC PLANNING/ADVOCACY COMMITTEE – Linda is the spokesperson for this group, and she asked Shelly to report the outcome of their efforts. Consensus was that staff will begin drafting a “Talking Points” document for Mark’s use in Washington D.C. Key points which will be contained in this document are: (1) value of IL services; (2) the

Approved

09/18/07

importance of the four core services; (3) the need for increased funding of IL services/programs; and (4) key legislative issues that the SILC believes are needed i.e., Reauthorization of the Rehab Act, ADA Restoration Act, Mental Health Parity Act, Section 8 Housing funding. Shelly will work on a “draft” and then work with the committee to further refine it. The next item was conversation on the committee’s role. After some lengthy dialogue, consensus was that the committee will be called “State Plan Advocacy Committee” and it’s role is: “The State Plan Advocacy Committee is the vehicle through which the SILC will monitor SPIL activities and identify advocacy efforts for the SILC’s consideration and action.” The final item was conversation on the SPIL Questionnaire results and the new SPIL. Consensus was that the revised goals, as drafted at the May 23<sup>rd</sup> meeting of SPIL signatories and CIL directors, are a good starting point for the writing of the new SPIL. As for strategies and actions, consensus was that members would look over current language and be back in touch with staff on any changes or recommendations they feel would fit under these new goals. Following the report, there was some conversation about the need for better and consistent reporting on accomplishments, so the value and benefits of IL become more readily known by all. Tom thanked both committees for their work and their reports.

DSS NEWS AND ISSUES: Marilyn Kinsman provided this report. As of May 1<sup>st</sup> an exhibit on “aging” is at the Discovery Center – “Amazing Feats of Aging”. It will be there until September, and she encouraged people to go down and experience it. Marilyn reported that the DSS long-term care study continues with various meetings being held to gather input. A preliminary report is expected some time in July, and the final report is expected to be in hand by the end of October. A report to the Governor and Legislature is due December 15<sup>th</sup>. The Departments of Health, Labor and Education are also playing a part in this study. DSS continues to work with Avera Health Systems on finding ways to meet the needs of more people with traumatic brain injury within South Dakota. They are also exploring better meeting the

needs of people needing wound care and who are ventilator dependent within the state. Finally, DSS has been busy with efforts relating to the flooding and other natural disasters, which recently occurred in our state.

SDHDA NEWS AND ISSUES: Vona Johnson shared this report. She spoke of their efforts in support of people impacted by the recent flooding and other natural disasters, which have resulted in major damages to homes and businesses in northeastern South Dakota. She had an opportunity to go up to Aberdeen, and until she got there, she didn't have a sense of the magnitude of the damage and devastation. She spoke to people not pursuing available assistance, because they believe there are others who need it more. It is becoming clear that many people will need counseling as a result of these occurrences and their impact. SDHDA is in the process of doing its five-year consolidation plan. As they prepare, they may wish to pull in specifically focused groups to attain their perspectives on the needs throughout South Dakota.

CIL REPORTS: Tom handed the meeting over to Linda Biffert, newly elected Vice-Chairperson. Linda asked for PFCIL to start this process. PFCIL – Matt reported. He spoke to the fact that they will be moving into a new building close to 49<sup>th</sup> and Louise, and the closing on the property is scheduled for June 5<sup>th</sup>. Matt explained how things have fallen into place, and as a result the new location is becoming a reality. He said they expect to move into the space the weekend of July 23<sup>rd</sup>. They will celebrate their 25<sup>th</sup> anniversary later this summer, and he invited the SILC to participate in these activities. He reported that they have served 859 people thus far this year. Their transition class begins June 18<sup>th</sup>, and they have 21 youth registered for this activity. They have raised \$6,700 in support of this week. Matt also reported that PFCIL raised \$16,875 through private grants and donations. He then spoke to their collaboration with Augustana and former legislator Elaine Roberts to host the "Lighting the Way" conference at Augustana. It focuses on autism and autism related

disorders. At the present they have over 200 people registered for the event. Matt also shared that the leaders at Augustana have asked them to complete a facility review of their campus. PCFIL and NCC PVA will be collaborating on completing this effort. Finally, Matt shared that PFCIL has been chosen as one of the top 20 best non-profits in Sioux Falls (as it appeared in the Sioux Falls Business Journal). Grady commented that the SILC has heard about the Youth Leadership Forum, the transition week at the Rehabilitation Center for the Blind and PFCIL's planned transition classes. He suggested that the SILC consider transition services being a larger part of the new SPIL development. OIL – Gary spoke to their efforts to assist people impacted by the recent flooding and other natural disasters. He shared some examples of assistance, which they and other have provided, as well as the magnitude of “stuff” being thrown out due to the flooding. He was surprised that the flooding did not significantly impact most of the individuals OIL serves. Gary reported that in the advocacy arena, they are presently physically assessing where curb cuts are and are not being placed. He shared that the State Department of Transportation has been holding community meetings in support of revising their ADA plan. He expressed that these meetings are a result of the problems experienced in Aberdeen when street and road construction were completed and accessible elements were not completed correctly. Gary shared that they are working on new policies suggested as a result of their annual audit. He also indicated that the 704 report software has been purchased, and each CIL will be working to have it installed and receive needed training. Finally, Gary spoke to the value of the CIL staff training event. He also shared that four of OIL's independent living specialists will be participating in the regional IL conference coming up in Wyoming. Grady suggested that DakotaLink may be able to provide some training assistance with the 704 report software, and DRS would find resources to support their involvement, if it needs to occur. CSD – Tom shared that all of their HMA and TAD funds were expended as of this morning. CSD is holding American Sign Language (ASL) classes for about 34 people, and they will provide further classes, as

the need is made known. Tom also spoke of their collaboration with SHIINE to train four individuals who are deaf to go out and train other members of the deaf community on these matters. Tom shared that they are working with Avera and Sanford to develop legislation that would require that health related videos/cds must be captioned, as well as include sign language interpreting as a part of the presentation. Gary shared that he saw “Through Deaf Eyes” on PBS, and it was an excellent show. Grady shared that DRS has purchased some copies of this show, and they will be available for others to borrow, once they arrive.

OTHER BUSINESS: Shelly asked if she could step out of role as SILC staff. Tom granted her permission to do so. Shelly, as Coalition Executive Director, shared news of the Road to Freedom Tour event being planned in Sioux Falls on July 6<sup>th</sup>. She reviewed some of the key elements of the event, and she invited SILC members and others in attendance to come and be a part of this event.

FUTURE ACTIONS: SCHEDULING OF NEXT MEETING – Linda asked when they would like the next meeting to be held. Consensus was that it would be held the first part of the week of September 18<sup>th</sup> in Pierre. Staff will work on specific arrangements, and notify SILC members of exact dates and location once they’ve been firmed up. ADJOURNMENT – Linda asked for a motion to adjourn. **MOTION TO ADJOURN – MSC.** Meeting adjourned at 10 a.m.